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XVI World Congress of Sociology

Durban, South Africa, 23-29 July 2006

The Quality of Social Existence in a Globalising World

Exploring the challenges and responsibilities of mutual engagement within participatory action research.

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Themes

- Participatory qualitative methodologies that centralize the voices of those most easily marginalized by mainstream policies
- Shaping the study methodology
- Key responsibilities of the co-researchers within this process of mutual engagement
- Challenges and responsibilities of identifying the perspectives of co-researchers in a methodology striving to mutually engage diverse communities of academic researchers, NHS clinicians and service users
- Issues emerging of relevance for policies on social exclusion, cultural competence and user involvement

Terminology

- '*Action Research*' = a research methodology based on learning-by-doing
- '*ARV*' = Anti-Retroviral medication (drugs thought to slow HIV replication and the onset of AIDS)
- '*RCT*' = Randomised Controlled Trial
- '*NASS*' = UK National Asylum Support Service part of the Home Office Immigration and Nationality Department
- '*National Dispersal Scheme*' or '*Dispersal*' = enforced & involuntary relocation of asylum seekers within UK
- '*Vouchers*' or '*Voucher Scheme*' = a stigmatizing state benefit system for asylum seekers that uses vouchers instead of cash

Aims

Share, implement and disseminate good practice through identification of:-

- clinicians/service users' perspectives;
- local knowledge that inhibits/enables subject engagement;
- factors that sustain adherence;
- factors that enhance local research capacity.

Research questions

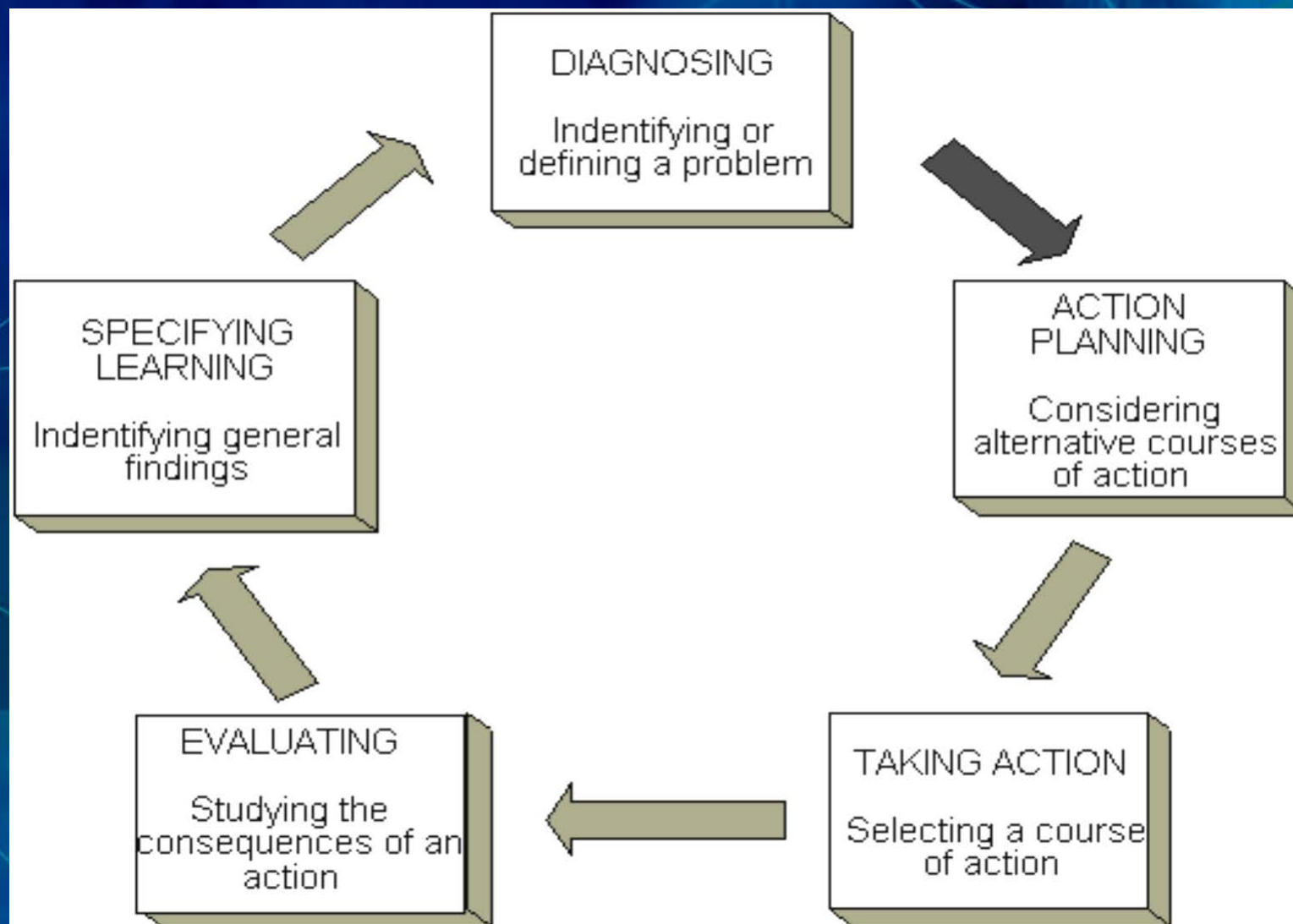
- what factors enable/constrain greater recruitment of HIV-positive London-based sub-Saharan African patients into anti-HIV clinical trials (ARVs)?;
- what factors facilitate/impede subject adherence whilst enrolled?;
- what service developments could accommodate above findings?;
- what inputs enhance social research capacity of research nurses?

Anticipated outcomes

- enhance enrolment strategies;
- increase African user consultation;
- developing clinical strategies in context of 'lay' health beliefs.

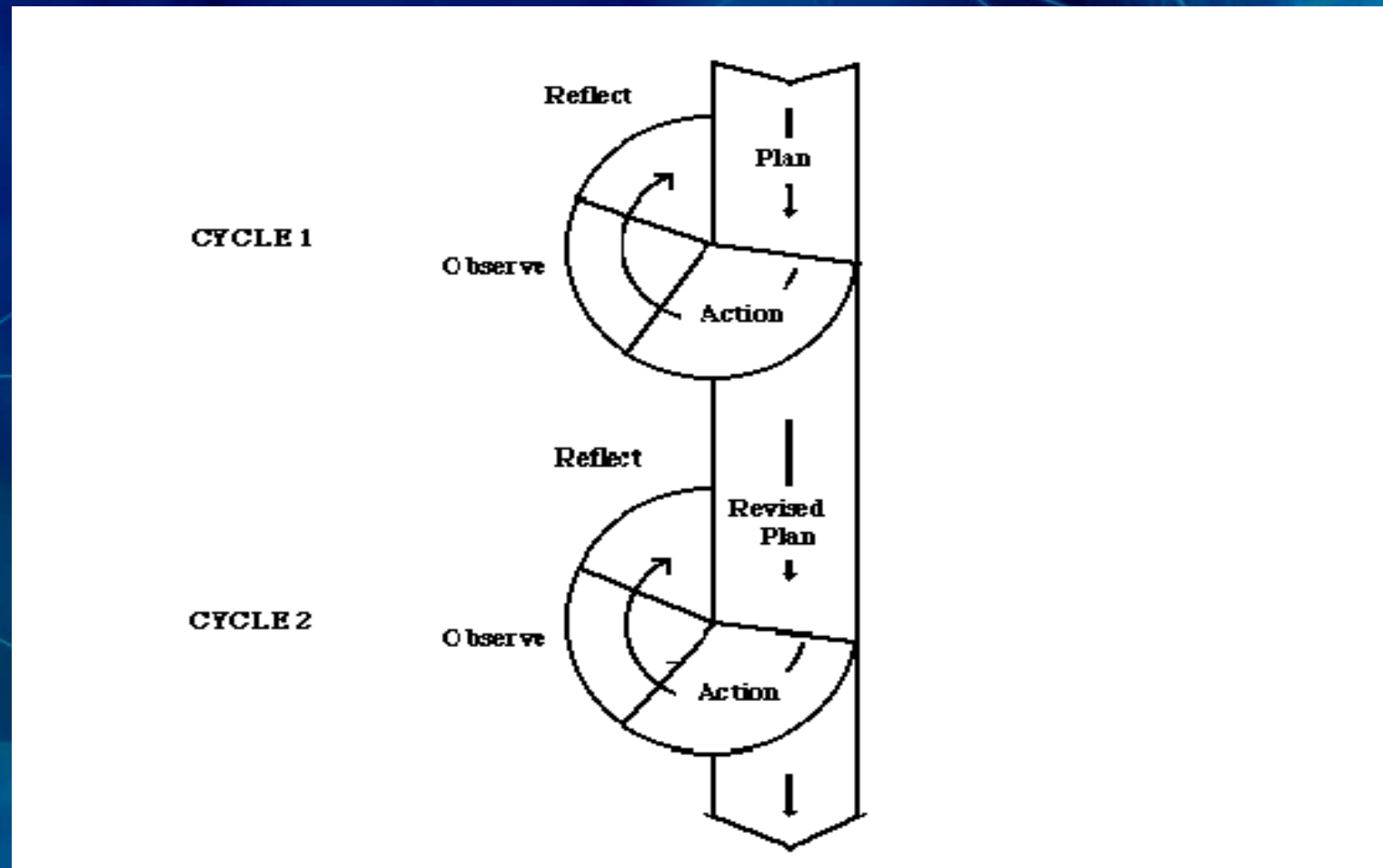
Action Research Process

(after Susman 1984)



Action Research Process

(after Kemmis 1985)



cited in Hopkins D (1985) *A teacher's guide to classroom research*.
Philadelphia: Open University Press

Participatory action research (after Stringer 1999)

- Participatory action research aims to be:
 - democratic
 - enables participation
 - equitable
 - acknowledges equality of worth
 - liberating
 - provides freedom from oppressive conditions
 - life enhancing
 - enables expression of individuals' full potential

Research advisory group (RAG)

- assists in achieving study aims/objectives
- forum to agree:
 - methodology
 - user involvement
 - data analysis
 - differing perspectives
 - social factors
 - ethical issues
 - funding
- invites participation of related communities
- engagement of related communities:
 - African professionals, users and patients
 - academic researchers
 - clinicians

Research advisory group (RAG)

→ Diverse communities of London-based African professionals, patients/users, academic researchers and clinicians with differing:

- roles/responsibilities
- tools & resources
- challenges
- interventions

Related communities of 'co-researchers'

Role/Responsibility

Tools & Resources

Challenges

Interventions

African users & patients

- inform research process
- active participation e.g. data, analysis, user involvement

- provide data, analysis of data
- marketing: help develop flyers, posters

- develop user forum

- local knowledge

- community networks

- experience of problem/part of solution

- knowledge levels

- NASS dispersal

- multiple economic challenges e.g. vouchers

- attitudes/belief systems

- confidentiality

- motivation levels

- invitation to RAG

- referral to Services

Related communities of 'co-researchers'	Role/ Responsibility	Tools & Resources	Challenges	Interventions
Academic researchers (co-opting Research Assistant & African professionals from within the African communities)	<ul style="list-style-type: none"> ■ facilitate funding bids ■ establish Research Advisory Group (RAG) ■ co-ordinate data collection & analysis ■ developing interview guide 	<ul style="list-style-type: none"> ■ research expertise ■ opinion leadership ■ knowing community based issues e.g. recruitment sites, CBO's ■ interview guide ■ African co-researchers 	<ul style="list-style-type: none"> ■ knowledge of community issues ■ representation ■ knowledge of methodology ■ sense of alienation ■ project schedule ■ in-depth interviews ■ validity & reliability 	<ul style="list-style-type: none"> ■ recruit (co-) Research Assistant from African communities with local knowledge ■ recruit to RAG ■ seminars ■ lobby NASS, DoH re: RAG issues

Related communities of 'co-researchers'

Role/Responsibility

Tools & Resources

Challenges

Interventions

clinicians
(physicians,
nurse specialists,
research nurses,
health advisors)

- provision of data
- analysis of data
- participate in developing user involvement forum

- patients' trust
- clinic setting
- opportunities

- attitudes
- power relations
- immigration status of patients
- overcoming perceived threats to professionals'/boundaries

- transparency of information
- invitation to RAG
- increase visits to the clinic
- more informal contacts

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- Research and Participatory Action Research (RAPAR), Greater Manchester
- African HIV Policy Network, London
- Department of Health Sciences, University of York
- Faculty of Health and Social Care Sciences, Kingston University/St George's, University of London

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